

They teach you how to deal with a dying child

By Sonora Jha Namblar

BANGALORE, June 22:

Five-year-old Niloufer's (not her real name) parents know that their daughter will soon die, but even more traumatic is their helplessness every time their daughter begins screaming with the devastating headaches caused by her cerebral cancer.

Since March this year, however, they have had some respite. Two women entered their home and their lives, and patiently taught them how to deal with a dying child.

In a scheme quite unique in India, members of the Bangalore Hospice Trust (BHT), unable to sit around waiting for their premises to take shape, decided to take up the not-so-popular cause of caring for the terminally ill from within the family. On Sunday, when Karnataka Governor Khurshed Alam Khan lays the foundation stone of Banga-

'He keeps them going'

The nurse and counsellor team that takes on the draining task of providing palliative care to terminally-ill cancer patients has recently been joined by a third member — the autorickshaw driver hired to take them around.

"When Shekhar Chary found out exactly what these women were up to, he plunged headlong into the task himself," says Kishore S. Rao, managing trustee of the Bangalore Hospice Trust. "On one occasion, when the two women were about to give up exhausted trying to locate a patient's address given to them by a doctor, he urged them to keep at it. When they could not get a lead, Shekhar Chary, who found out that the patient was a Muslim, went to the mosque nearest the address given, approached the *mulla* and traced down the patient." This man, in fact, has been a source of inspiration to the home-care team which must witness each day, the draining effect minding those destined to die within a few months.

lore's first hospice, on Airport Whitefield Road, the movement will only be strengthened, says BHT managing trustee Kishore S. Rao, speaking to *The Times*

of India.

Niloufer's is just one of the cases that the BHT's home-care team is handling. On May 19, in fact, the two-member team vis-

ited the home of its 100th patient. Of these, 78, so far, have died, as the doctors said they would but not as miserably as such people had in the past.

This home-care team has the unenviable job of collecting names of terminally ill cancer patients from the oncologists in Bangalore, tracing down their address and then entering their homes so that they can provide palliative care. This palliative care moves the emphasis to 'caring' when all hope of 'curing' has been lost. Which means that Nurse Jose Mary can provide medical intervention to ease the pain and counsellor Usha Shinde can help the patient and the family drain out their emotions.

"The philosophy is to value life until death," says Mr Rao, "and to give the dying the dignity of breathing their last in surroundings of their choice. The motive is — peaceful end."

Which means that when a nine-year-old has cancer of the bones with an exposed tumor on the knee which begins oozing and amputating, and the doctors have sent her home to die, and the family has nowhere to take this very physical and emotional problem, the home-care team steps in.

Cutting across age, class and income-group differences, the home-care team's patients will soon also have the option of ending their lives in a 57-bed hospice set up for them, which will provide, free of cost, care that is not available at home.

The hospice, being set up on five acres of land given free by the Karnataka government, will provide personal care, emotional support, respite care, financial and legal planning advice, symptom control, appropriate nutrition, bereavement support and medical supplies and equipment.

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